Indiana Mental Health and Addiction Transformation Work Group
Consumer/Family Sub-Committee Presentation December 12th, 2006

"If we were planning something for women, would we not have any women at the planning table? If we were planning programs for African Americans, would there be only one African American at the meeting?" A transformed system will have involvement of the consumer and family that is part of an overall organizational management strategy, rather than a series of ad hoc projects. That is, the state will have Inclusion as part of a top down commitment to a Continuous Quality Improvement process that is an ongoing task force with consumer and family membership (not just for a particular case without consideration of ongoing quality improvement applications). It will include numerous individuals with lived experience in the design and implementation of culturally competent services as well as professional training programs for providers on Recovery and Resilience.
DMHA will involve the state consumer and family organizations in recruiting and selecting who represents their voice in these tasks. Consumers and their families will be included in <u>every</u> DMHA, state hospital and state contracted community provider policy and planning meeting. All partners will be treated equally; i.e., whenever providers or other stakeholders are invited, consumers and families will be at the table. There will be no Tokenism – a sufficient number of individuals representing consumers and families will be invited so that individuals feel free and safe to speak up in the group, and dissent of their opinions will be expressed in a respectful manner. The consumer / family voice will be listened to and respected for its experiential knowledge.

The state will involve Consumers & Families at the beginning of projects in helping to develop a clearly defined purpose, mission or task of the group as well as clearly defined expectations, roles and responsibilities of the participants. There will be a spirit of collaboration - well defined goals which consumers and families helped to define, and real progress towards goals, using strategic planning, in order to sustain involvement. We will see consumers involved in the implementation of the meeting, program or presentation, and inclusion of consumers and families in developing the content of the agenda and other documents and setting the time /location for the meeting.

In this system, the consumer and family voice will be actively involved in evaluation at the systems level, including the evaluation of state Hospital providers, local community providers and the evaluation of the Division itself. There will be a minimum of two consumers who are not mental health service providers on evaluation teams to avoid tokenism. Consumers and families will be highly involved in designing the outcomes which will be evaluated, reviewing all requests for proposals for the evaluation contracts; recruiting the consumers and families who will be involved; deciding about the management of the evaluation budget; identifying training needs of the evaluation team; conducting the evaluation interviews; analyzing data; interpreting data; identify findings; and Reporting results to consumers & families, to providers, to the local community and to the state community (i.e.: regional TA meeting presentations)

What do consumers and families need to be full partners in service delivery? A Public Health Prevention / Early Intervention Approach promotes health and safety and offers hopeful, safe, warm treatment environments that facilitate trust. Treatment with dignity and respect, including respect for cultural diversity, encourages ongoing engagement in the treatment process. Treatment that is free of labeling or discrimination based on a diagnosis or disease decreases a sense of stigmatization. No person is a schizophrenic, a borderline, or a multiple, and we are not the mentally ill. Being addressed as People first, and treated in the same manner as we would if we had any physical illness, tends to makes us feel as if we have a "normal" chronic condition. Treatment which universally welcomes all, even the most difficult to serve or dually diagnosed, no matter which door we come through, is cost effective to society.

When we experience an individualized, culturally competent, inclusive treatment process, receive education about our diagnosis or disorder and information, resources and a range of treatment options to exercise choice, we experience a sense of empowerment and success. Empowerment to direct our own healing and to drive all phases of treatment planning furthers our self esteem. When consumers and parents or primary caregivers are regularly included in treatment planning meetings and have access to layman's terminology during those meetings, we achieve better outcomes.

A holistic approach which values our unique strengths and attributes is more likely to sustain long term engagement in the treatment process. If there is an emphasis on resilience and recovery processes as opposed to pathology and disease processes and recognition of multiple long-term pathways and styles of recovery, we flourish in our lives. Changing the service relationship from an acute care model to the recovery model in a long-term health care partnership assists healing. Providers who promote self-advocacy, personal responsibility and self-determination have more time to provide services to others. Healthy expectations of positive outcomes and clinicians who see Recovery as a non-linear process and that an occasional setback is not a failure support our success.

Partnership and empowerment which allows us to be in control of our treatment assists us in taking personal responsibility for our condition. An environment which avoids the use of coercion and re-traumatization, one which allows us to learn to increase self management of our illness and build resiliency, where we are encouraged to achieve an improved sense of mastery over our condition, helps us to move on with our lives. We thrive in an environment and primary culture transformed from one of "Control" to a recovery model which relies heavily on individual trauma-informed assessment and treatment to reduce and ultimately eliminate seclusion and restraints.

PART A. POLICY DEVELOPMENT RECOMMENDATION 1:

Indiana will have full Consumer and Family (C / F) Inclusion as part of a top down commitment to a Continuous Quality Improvement process that is an ongoing task force with consumer and family membership.

Strategies to Achieve Inclusion:

1. Routinely & universally seek to Identify cultural / linguistic needs (i.e. interpreters, Bobbie Approved website) a process in place to support those needs
2. Act on the strategies recommended in the NMHA Position Statement Cultural and Linguistic Competency in Mental Health Systems
3. Act on the strategies recommended in the DMHA Position Statement On Stigma And Discrimination Against People With Alcohol And Drug Problems
4. Train system staff, including DMHA staff, in use of Person First Language
5. Include C/ F in <u>every</u> DMHA, state hospital and provider planning meeting.
6. Treat All partners equally; whenever providers are invited, C/F will be invited.
7. Eliminate Tokenism – invite a sufficient number of individuals representing C / F so that individuals feel free and safe to speak up in the group.
8. Include a minimum of at least two consumers who are not also mental health service providers on every team to avoid tokenism.
9. Create an Office of Consumer and Family Affairs within DMHA senior management, headed by a Deputy Director who reports directly to the DMHA Director, with a minimum additional staff of three
10. Involve C / F in
    - evaluation of Hospital & community providers
    - designing outcomes to be evaluated
    - reviewing proposals for evaluation contracts
    - recruiting C / F who will be involved
    - decisions re management of evaluation budget
    - identifying training needs of evaluation team
    - conducting evaluation interviews
    - analyzing data
    - interpreting data
    - identify findings
    - reporting results to local / state community

POLICY DEVELOPMENT LEVEL RECOMMENDATION 2:

Provide Information to fully Inform Stakeholders (in the consumer's / family's language)

Strategies to Inform Stakeholders:

1. Provide Orientation to new members prior to meetings at the meeting location
2. Send official invitations at least 30 days in advance, which include objectives for the meeting, meeting agenda, documents to be reviewed, logistical information
3. Involve the Consumer and family state organizations in recruiting and training consumer/family member representatives to make effective inputs at the planning venues, to ensure our inputs are effective and reflect our consensus interests
4. Implement a Continuous Quality Improvement process which includes a formal feedback process regarding progress on advisory groups' recommendations.

POLICY DEVELOPMENT LEVEL RECOMMENDATION 3:

Provide Supports Needed To Fully Involve Consumers and Families

Strategies to Support Stakeholders:

1. Provide Supports:
    - to eliminate stereotypes and to battle tokenism; develop the Readiness (through self assessment) of the organization /community to support us
    - of reasonable accommodations for those who may participate with different levels of intensity or at different times depending on our outside obligations
    - of financial compensation for our time and experience-based expertise:
        A. stipends to offset loss of wages
        B. Transportation/mileage expenses / Lodging
        C. Meals
        D. Dependent care is provided for mental health care givers
        E. Meeting locations with Free and Available Parking
        F. Allow members to participate in meetings by conference call for members who are unable to attend in person. Arrange for a toll free multi line conference call for meetings.

PART B. SERVICE DELIVERY LEVEL RECOMMENDATION 1:

Indiana will have an individualized, culturally competent, inclusive treatment process that is driven by the needs of the C/ F.

Service Delivery Strategies to Achieve Inclusion:

1. Consumer has a qualified interpreter if he/she does not speak the local language.
2. Consumer has mental health education materials in their native language / Braille.
3. Consumer has right to access information on a Bobby Approved FSSA website
4. Develop a strategic plan to increase culturally competent care
5. Integrate the use of Recovery Programs into the system through workforce development, support, funding, and fidelity monitoring and outcome measurement. Promote nationally recognized Recovery programs, i.e.: Children's Systems of Care; Creating Violence Free and Coercion Free Treatment Environments; Roadmap to Reduction of Seclusion and Restraint; Illness Management and Recovery; Wellness Recovery Action Planning (WRAP); Pathways to Recovery, University of Kansas; Use of Person First Language; Bienvenido Program; Crisis Intervention Training CIT; Sanctuary Model (Sandra Bloom); Social Learning Model (Gordon Paul)
6. Provide workforce training in
    - Linkage to natural supports in our community
    - how to assist us to regain meaningful membership in the community
    - understanding of / respect for quality of life issues for all team members
    - how to assist us with supported education and supported employment
7. DMHA should request NASMHPD technical assistance center come to Indiana to teach the Trauma – informed Care Train the Trainer curriculum. DMHA should create a state policy on Trauma-informed care.
8. Require the use of one statewide standard assessment process across all systems which identifies all disorders in order to plan individualized care, inform level of care, is trauma-informed, determines need for admission to and discharge readiness from an SOF, and measure outcomes- standardize care levels statewide. Assessment for SOF level of care should be done by an independent evaluator that is not employed or connected with the Gatekeeper, and does not have a financial or vested interest in removing the individual from the community or in admitting the individual to an institution.
9. Require all community agencies to provide and / or locate appropriate needed services for all individuals, including co-occurring substance disorders/ physical disorders / developmental disorders, including persons with autism or Aspergers.
10. DMHA should have meetings with consumers to discuss changing the psychiatric advanced directive code *IC 16-36-1.7-5* "This chapter does not preclude an attending physician from treating the patient in a manner that is of the best interest of the patient or another individual."

SERVICE DELIVERY LEVEL RECOMMENDATION 2:

Provide information to fully inform stakeholders (in the consumer's / family's language)

Service Delivery Strategies to Inform Stakeholders:

1. Provide information on Rights and /or referral to community resources, including:
- ✓ Basic human and civil rights advice, advocacy services
- ✓ Education on rights under the ADA, IDEIA, FHA and WIA
- ✓ Opportunities to learn Self-advocacy, leadership and Negotiation skills
- ✓ Training on reasonable accommodations: housing, education, employment
- ✓ Information on legal avenues and options such as psychiatric advanced directives and durable medical power of attorney
- ✓ Patients rights under the Gatekeeper rule and the community care rule, and of the grievance procedures to follow when care requirements are not followed
- ✓ Rights under Olmstead and the ADA for community integration, and access to an attorney if needed
- ✓ Where I am on the DMHA Olmstead Plan waiting list to be released from the hospital and reintegrated into the community
- ✓ Costs which are going to be charged to consumer in a community treatment center as well as to the patient under commitment to a state operated facility
- ✓ Benefits / financial counseling or planning provided by the hospital staff in accordance with state statute

2. Print pamphlets/ booklets with information on patient rights / responsibilities
3. Fund C / F family organizations to provide rights training to their constituencies
4. Require patient signed form that they are informed of the costs they are incurring
5. Require patient signed form that they have received the benefits counseling; form must state manner in how the accrued expenses will be paid, i.e., "Patient will pay $200 per month for the next 36 months upon release from state operated facility."

SERVICE DELIVERY LEVEL RECOMMENDATION 3.

Provide supports needed to fully involve consumers and their families

Service Delivery Strategies to Support Stakeholders:

1. Create a policy where peer support for mental health services in both the adult and children's arenas is a Medicaid billable service
2. Make use of Peer-led consumer organizations that already have developed training programs for consumers/providers and continue utilizing this resource in developing new programs.
3. Create a funding stream to allow support of including consumers and/or family members to participate at ALL levels. Examples of how to fund might be:
    - Add a budget line in the State Mental Health Block Grant for a fund
    - Propose that a 1% tax be created to support the effort;
    - Endorse fund-raising events to promote resiliency – May is an appropriate time – it is Mental Health Month, or October, which is Recovery month – maybe two events a year – proceeds are tax deductible'
4. Create Opportunities to use the consumer/family experiential expertise in providing peer support services in hospitals
5. Use the consumer/family experiential expertise in training the workforce
6. Change the Indiana state contracting process: preference for minority and women owned businesses- add preference for person with disability owned businesses
7. Collect data on length of time required to access of services
8. Create a Policy giving the right to change providers/ money follows the person
9. Use data to inform the extent of use of state operated facilities and the criminal justice system as de facto treatment settings in lieu of providing adequate and appropriate community care in the least restrictive setting; use this data to incorporate outcomes measures and quality improvement processes in performance based contracting with providers
10. Use interagency collaboration to encourage housing funders/ developers to provide a real choice of a variety of residential living options with supports

Specific Service Delivery Strategies for SOF:

1. Create an Olmstead Community Integration policy which requires that all Treatment be provided in the least restrictive community environment
2. Create a policy that patients will no longer be charged for treatment fees once level of care reaches discharge criteria – no institutional level of medical necessity
3. Protect involuntary patients from victimization, including harassment, assault or rape in the state operated facilities. The inclusion of predator type populations on hospital grounds is of great concern. Such populations should be excluded from the SOF when at all possible to decrease further victimization. Place all convicted perpetrators on one campus with physical barriers from non-predatory patients.
4. Persons in state operated facilities who meet the standards for care in an ICFMR (Intermediate Care Facilities for the Mentally Retarded) are given a higher standard of human rights care than persons with SMI level of care. We believe the Division should make it a policy that All consumers in state operated facilities should be provided human rights care under the higher ICFMR standards. Hospital Human Rights Committee's at SOF should be composed of people who are not hospital employees or connected to the hospital in any financial way.
5. Create a policy that when SOF's conclude that an incident of abuse/neglect has occurred, they should be required to report to the local Police.
6. 6. DMHA should adopt a policy that SOF staffing levels should maintain current based on the average of recent Department of Justice decrees of similar facility's and reviewed every five years.
7. Pass legislation which allows a person found Incompetent to Stand Trial who cannot have their competency restored to be able to return to the community.
8. Gatekeepers should be provided a list of all consumers who are in prison/jail who are receiving psychiatric/psychological interventions at least two months in advance of their discharge date to ensure continuity of care. The gatekeeper rule should be changed to define what a reasonable pace is for waiting on the waiting list for community placement
9. DMHA should have meetings to discuss whether "Gravely Disabled" should no longer be a reason for Civil Commitment.
10. **We would like to see the elimination of discriminatory practices /policies (other than those that restore competency as prescribed by law) that place restrictions on consumers based solely on the fact that they are committed to a State Operated Facility. Examples of such practices include being placed on an unwanted diet when competent to make healthcare decisions, being provided no area to smoke cigarettes if competent to make that decision, no appropriate accommodations to have conjugal relations, and being restricted from privileges for behaviors that are not dangerous to self/others. We do not feel that such practices are consistent with a strengths based, Recovery oriented service system.**

Reasoning behind Strategies

4. Currently there are two distinct levels of care in the State Operated Facility's. The Intermediate Care for Mental Retardation (ICFMR) standards for the consumers who are developmentally disabled and on certified ICFMR units and Joint Commission on Accreditation of Healthcare Organization (JCAHO) standards for consumers with mental illness. The ICFMR standards provide much more extensive detail in what is required and provides a broader understanding of consumer rights. While it is understandable why, given the history of advocacy, this is the case, the fact that disability rights are fragmented depending on the specific type of disability is pejorative and discriminatory. Consequently, we believe that both groups should be unified by assuming the more stringent ICFMR standards. This in no way takes away from the fact that JCAHO will still be in charge of reviewing the standards. JCAHO ensures that SOF's maintain JCAHO's minimal standards and/or, when the SOF's have more stringent standards, maintain their own more stringent standards. This change alone will afford consumers with many more rights than they now have and will demand more focused treatment then is currently provided. It would also likely impact staff consumer ratios.
(Examples of differences; 1) In ICFMR = any restriction must be reviewed by Human Rights Committee, JCAHO does not require such; 2) In ICFMR progress must be reviewed monthly, quantitative data must be reviewed, if no progress treatment must be changed, JCAHO requires quarterly review with no stipulation in regards to specific quantitative measurement and no progress needing to result in treatment change.)

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5. Current policies/practices regarding abuse incidents do not protect consumers. Staff who engage in abuse are not prosecuted according to law and while APS follows the letter of the law, they do not follow the intent. SOF's rely on APS to do this and it is not done. The APS law mandates that someone does an investigation into abuse incidents. APS uses the SOF's internal investigation as the sole review and does not question the sanctions placed on by the SOF. This allows each SOF to, at times, find that abuse occurs but not terminate or, if they do terminate the individual, they do not prosecute consequently, the individual will have no record and are allowed to obtain employment working with disabled individuals in the community.

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4. The Recovery Movement came directly out of the Human Rights movement. Currently, SOF consumers are not fully protected from human rights violations. In part this is due to the fact that the Human Rights Committee is a hospital committee with the majority of members being hospital staff. Such staff are both overtly and covertly blind to rights issues. Consequently, it suggested that members be external to the hospital, with only non-voting hospital members present to carry out the committee rulings.

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6. Currently some Indiana State Operated Facility's are basing their staffing levels on 1984 Department of Justice Degrees. If a medical doctor based his/her decisions on 1984 data they would be found guilty of malpractice. SOF staffing levels should maintain current based on the average of recent DOJ decrees of similar facility's and reviewed every five years.

Forensic Issues

7. Currently Indiana does not have a means for people who have been found Incompetent to Stand Trial to be released, unless they become competent or their charges are dropped. There are those individuals whose charges are serious but have not engaged in any violence since that time who have remained incompetent and will not likely regain competency. Historically, prosecutors are hesitant to drop such serious charges despite a long history of no violence in the institution. Florida law has a means to address this issue that is both sensitive to the societal and consumers need. It seems prudent for Indiana to reflect such a practice as well. That law, 916.145 in the Criminal Procedure & Corrections Title XLVII under **Dismissal of charges** states, "The charges against any defendant adjudicated incompetent to proceed due to the defendant's mental illness shall be dismissed without prejudice to that state if the defendant remains incompetent to proceed 5 years after such determination, unless the court in its order specifies its reasons for believing that the defendant will become competent to proceed within the foreseeable future and specifies the time within which the defendant is expected to become competent to proceed. The charges against the defendant are dismissed without prejudice to the state to refile the charges should the defendant be declared competent to proceed in the future." In practice, if the consumer showed behaviors of decompensate/violence, the charges would be brought again and in this way all parties were protected.

8. The gatekeeper law does not provide for services to those in prison. Given the large number of consumers who are in prison we believe that Gatekeepers should provide continuity of care for all consumers, no matter what system they are currently in. Consequently, we would ask that Gatekeepers be provided a list of all consumers who are in prison/jail who are receiving psychiatric/psychological interventions at least two months in advance of their discharge date. In this way, providers can better prepare for services and meet with such individuals to access their needs.

9. "Gravely Disabled" - the term gravely disabled is too broad and allows people to be committed who do not pose any significant danger to themselves or others. It has issues of being "unable to provided for that individual's food, clothing, shelter, or other essential human needs" which has, at times, been interpreted to mean that if someone does not have a job or does not have a place to stay they should be committed. In such cases, the person is either admitted to a state facility or caused to remain there when they do not pose a danger to themselves or others. We believe there should be discussions regarding whether this should be changed.

IC 12-7-2-96 Gravely disabled Sec. 96. "Gravely disabled", for purposes of IC 12-26, means a condition in which an individual, as a result of mental illness, is in danger of coming to harm because the individual: (1) is unable to provide for that individual's food, clothing, shelter, or other essential human needs; or (2) has a substantial impairment or an obvious deterioration of that individual's judgment, reasoning, or behavior that results in the individual's inability to function independently.

As added by P.L.2-1992, SEC.1.